Monitoring and discussing health related quality of life in adolescents with type 1 diabetes in routine practice

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2008

document version
Publisher's PDF, also known as Version of record

Summary

Type 1 diabetes is a chronic auto-immune disease for which currently no cure is available. The treatment consists of replacement of the lacking hormone insulin by injections or pump therapy. The majority of diabetes care takes place outside the hospital, at home. For younger children, the parents are responsible for the management of diabetes, but this responsibility shifts to the children during puberty. However, many adolescents experience a deterioration in metabolic control, often attributable to endocrine changes associated with puberty, leading to greater insulin resistance, erratic meal and exercise patterns, poor adherence to treatment regimens and risk-taking behaviour. Although strict glycaemic control is found to beneficial in delaying the onset of complications later in life, teenagers are typically focused in gratification of their current psychosocial needs, rather than avoid health risks on the long term. The demands of daily self-care can easily interfere with normal routines and friendships, thereby compromising emotional and social well-being. Attaining strict glycaemic control as well as good quality of life is a challenge for adolescents with diabetes, their families and health care providers.

Quality of life has become increasingly important in health care practice and research. The term 'health related quality of life' (HRQoL) narrows quality of life to aspects relevant to health. However, HRQoL is a comprehensive and complex concept for which no universally accepted definition is available. General consensus is that it is a multidimensional concept which describes the physical, role, social and psychological aspects of well-being and functioning from the patients' perspective. HRQoL outcomes can guide decisions on alternative treatments or effectiveness of interventions at a patient group level. From the individual patient perspective, HRQoL outcomes can guide the choice of best treatment, made by the patient him/herself and the health care professionals. Evaluating the impact of diabetes on the adolescents' HRQoL and vice versa can help both the teenager and paediatrician decide on the optimal individual treatment. There is a wide variety of measures available to assess the HRQoL in teenagers with diabetes, divided in generic and diabetes-specific measures. In adult populations, the implementation of monitoring and discussion of HRQoL in routine care has yielded positive results. In paediatric care, periodic evaluation and discussion of the adolescents' HRQoL is recommended to ensure recognition of the teenagers' perspective, identify psychosocial barriers and promote healthy coping, but has not been previously studied.

This led to following research question:

Does monitoring and discussing the HRQoL in adolescents with type 1 diabetes in routine care improve their psychosocial well-being, satisfaction with care and glycaemic control?

The research project reported in this thesis sought to answer this question in a multi-centre randomised controlled trial, preceded by preparatory studies.

At first, we set out to identify and review the clinical utility of available generic and diabetes specific HRQoL questionnaires suitable for use in adolescents with type

1 diabetes. Literature databases were searched to identify HRQoL questionnaires suited for use in adolescents with diabetes. Self-report measures were reviewed for user instructions, content and psychometric properties to ascertain feasibility in clinical practice. In **Chapter 2**, four generic and five diabetes specific questionnaires were identified and evaluated. The reported validity and reliability of the generic questionnaires are good, but responsiveness (sensitivity to change) was only reported in two generic HRQoL instruments. Diabetes specific questionnaires have good face validity but construct validity and responsiveness need to be further established. We concluded that there are psychometrically sound generic and diabetes specific HRQoL questionnaires available, which are suitable for use in clinical practice. The responsiveness of most instruments warrants further research. For routine use, standardisation of HRQoL measurement should be sought to make comparisons across centres and countries. The PedsQL and the KINDL-R appeared, at that time, to be the most suitable instruments for implementation in routine practice. For this study we chose the PedsQL generic and diabetes modules and used a computer program for filling out the questionnaires. This ensured complete data and gave the possibility to calculate and print out subscale scores immediately.

For the main study, we recruited adolescents with diabetes from four paediatric outpatient clinics in the Netherlands. Ninety-one families consented to participate. Mean age at the start of the study was 14.7 years, mean diabetes duration 6.4 years and mean HbA_{1c} was 8.8% (range 6.2 – 15%). Almost one-fifth of the teenagers lived in a one-parent family and 10% of the adolescents were from an ethnic minority. **Chapter 3** described the baseline levels of physical and psychosocial well-being of the participating adolescents by self- and parent-report. These cross-sectional data showed that adolescents with type 1 diabetes report their well-being equal to a Dutch school population. Fewer diabetes-specific family conflicts were associated with better psychosocial well-being and less depressive symptoms. Parents reported more behavioural problems than the adolescents themselves did. Living in a one-parent family, being member of an ethnic minority and reporting lower well-being were all associated with higher HbA_{1c} values.

Although we did not find elevated levels of depression in our population, other studies have reported the prevalence of depression in adolescents with diabetes to be elevated. However, HRQoL measures are not developed as a screening instrument and an additional short screening measure could be necessary. The WHO-5 is a short, positively worded questionnaire that proved to be suitable for this purpose in adult populations. In **Chapter 4**, the validation of the WHO-5 well-being index in our participating adolescents is described. We concluded that the WHO-5 is a brief, patient-friendly measure of positive well-being with good psychometric properties that appears suitable for routine use in adolescents with type 1 diabetes.

The main effects of monitoring and discussion of HRQoL in adolescents with type 1 diabetes were tested in a multi-centre randomized controlled trial, described in **Chapter 5**. The four centres were randomly assigned to the HRQoL intervention or control group, with three regular visits scheduled within 12 months in both groups. In the HRQoL intervention group, HRQoL of adolescents was assessed prior to their

consultation using the PedsQL. Outcomes were discussed face-to-face during the consultation with the paediatrician or nurse. The control group received care as usual. It was concluded that periodic monitoring and discussion of HRQoL in adolescents with diabetes was appreciated and had positive effects on their psychosocial well-being, especially in less behavioural problems, better mental health, self esteem and involvement in family activities. However, those in poorest glycaemic control seemed to profit less.

Whether the positive effects are maintained without a formal HRQoL assessment or not, was described in **Chapter 6.** Those adolescents who had finished the HRQoL intervention were followed for another year, while receiving care as usual. The conclusion was that the beneficial effects of an office-based intervention in adolescents with diabetes were largely disappeared one year after withdrawing the HRQoL assessment procedure. This finding underscored the importance of including periodic assessment of HRQoL using standardized questionnaires in care for adolescents with diabetes.

Based on the findings summarized above, the main conclusions of this thesis are:

The level of well-being of teenagers with diabetes is not different from that of teenagers without diabetes according to the adolescents themselves and their parents.
Still, monitoring and discussion of HRQoL in routine practice has a positive effect on the psychosocial well-being of adolescents with type 1 diabetes as well as their satisfaction with care, but not glycaemic control.
However, the positive effects do not sustain in the absence of the computerised assessment procedure. This suggests that formal assessment of HRQoL is crucial to maintain optimal well-being and glycaemic control.